# INSTITUTE FOR TRANSLATIONAL NEUROSCIENCE AT NORTHWESTERN MEDICINE LES TURNER ALS RESEARCH AND PATIENT CENTER AT NORTHWESTERN MEDICINE

# LES TURNER ALS RESEARCH AND PATIENT CENTER AT NORTHWESTERN MEDICINE

Northwestern University Feinberg School of Medicine is known the world over for leading groundbreaking ALS (amyotrophic lateral sclerosis) research and for providing exceptional care and support to patients and families living with this debilitating and complex disease.

ALS, also known as Lou Gehrig's disease, is a progressive and fatal neurodegenerative disease that often strikes people in the prime of their lives. Anyone can be diagnosed with ALS: a mother, a son, a sister, or a grandfather. ALS affects an estimated 350,000 people worldwide, with an average survival of three years. The degeneration of nerves leads to muscle weakness and impaired speaking, swallowing, and breathing, eventually causing paralysis and death. The effects are devastating, and currently there is no cure.

With respected and high-impact programs in ALS, Northwestern Medicine is setting the pace in the field of ALS and is offering new hope for the future of ALS care, research, training, and outreach. Recently, we proudly announced the creation of the **Les Turner ALS Research and Patient Center at Northwestern Medicine**. This breakthrough Center was launched with the support of the Les Turner ALS Foundation—a steadfast partner with Northwestern for 35 years. Northwestern and the Les Turner ALS Foundation are now leading a major effort to raise \$10 million in funds to fully endow this new Center in perpetuity.

The Les Turner ALS Research and Patient Center will accelerate research and advance patient care in ALS. The Center will bring together the world-renowned Les Turner ALS Foundation Research Laboratories, the Les Turner/Lois Insolia ALS Center, the ALS Tissue Bank, and other ALS research, clinical, and education activities at Northwestern under one comprehensive umbrella. The Les Turner ALS Research and Patient Center is part of the Ken and Ruth Davee Department of Neurology and will operate under the Institute for Translational Neuroscience at Northwestern Medicine.

Thanks to the Les Turner ALS Foundation's partnership and philanthropic commitment over the years, Northwestern Medicine has been able to contribute significantly to scientific discoveries and medical treatment for ALS throughout Chicago and across the globe. This impactful relationship has helped Northwestern scientists to establish themselves as leaders in ALS research, both ensuring that the future for those fighting ALS is brighter and accelerating the progress towards ending the disease. The Les Turner ALS Foundation was founded in 1977 and is one of the nation's preeminent organizations dedicated to treating and finding a cure for ALS, serving approximately 90 percent of the ALS population in the Chicago area.

#### **Research to Find Answers and Provide Hope**

Northwestern has a foundation of excellence in ALS research and has contributed significant advances from the laboratories of Teepu Siddique, MD, the Les Turner ALS Foundation/Herbert C. Wenske Foundation Professor, and P. Hande Ozdinler, PhD, assistant professor of neurology.

Dr. Siddique's visionary leadership of the Division of Neuromuscular Disorders has helped to build a strong platform and tremendous momentum for the research activities and programs of the new Les Turner ALS Research and Patient Center. As a lead principal investigator, his laboratory has made several important discoveries in the field of ALS over the years, including the identification of genetic causes of ALS. Dr. Siddique's discoveries provide potential targets for drug therapy and show that all types of ALS are tributaries, pouring into a common river of cellular incompetence.

Most recently, he and his colleagues have created the first animal model of ALS dementia in mice, which will allow



'The advantage of having all of the research and clinical activities joined as part of the Les Turner ALS Research and Patient Center is to enhance collaborations between our researchers and clinicians and, therefore, facilitate the development of new therapies for ALS."

Dimitri Krainc, MD, PhD, Aaron Montgomery Ward Professor of Neurology and Chair, Ken and Ruth Davee Department of Neurology and Clinical Neurological Sciences



### Dr. Teepu Siddique

them to directly monitor drugs they are testing to determine how they affect the brain. In the study published in the *Proceedings of the National Academy of Sciences*, the team successfully reproduced behavioral, neurophysiological, and pathological changes in the mouse that mimic the type of dementia associated with ALS found in humans. According to Dr. Siddique, this new model will allow rapid testing and direct monitoring of drugs in real time, and will allow scientists to move quickly and accelerate the testing of drug therapies.

Dr. Ozdinler is one of the few scientists in the nation who studies cortical spinal motor neurons in ALS. These are the cells responsible for collecting, integrating, and translating signals from the brain before transmitting the information to the spinal cord, which then initiates a voluntary physical action by the body. It had previously been thought that the spinal motor neurons died first and their demise led to the secondary death of the brain's motor neurons. Dr. Ozdinler's research showed, however, that the motor neurons in the brain and spinal cord die simultaneously.

A third ALS research laboratory is being launched at Northwestern under the leadership of Evangelos Kiskinis, PhD, who has been recruited from Harvard and is joining the Davee Department of Neurology in January 2015. Dr. Kiskinis is a talented investigator who is addressing fundamental aspects of the neurobiology of motor neurons and the degenerative processes that target the neuromuscular circuitry as a result of genetic disease and natural aging processes. He is particularly interested in understanding the molecular mechanisms that underlie the degenerative process of motor neurons in ALS. In laboratory studies, he and his team have used stem-cell based approaches to investigate the processes that give rise



## Dr. Hande Ozdinler

to the genetic types of ALS. At Northwestern, he and his colleagues will work to understand the level and nature of heterogeneity in ALS and to identify points of effective and targeted therapeutic intervention. He will conduct these research projects using a combination of in vitro, stem cell-based approaches and global genomic assays and in vivo mouse models of the disease.

#### Patient Care and Support that Makes a Difference

Northwestern and the Les Turner ALS Foundation are proud to be a part of bringing world-class care to people living with ALS in Chicago and surrounding areas. Northwestern was recently ranked by *U.S. News & World Report* as one of the top 10 hospitals nationwide for neurology and neurosurgery, making it the top-ranked Chicago area hospital in this specialty.

The Les Turner/Lois Insolia ALS Center at Northwestern in Chicago was established in 1986 with funds from the James V. Insolia Family Foundation and the Les Turner ALS Foundation. It is part of Northwestern's Ken and Ruth Davee Department of Neurology. Through the multidisciplinary clinic directed with distinction by Robert Sufit, MD, our specialists use a team approach to provide comprehensive treatment. The clinic is dedicated to the total care and support of people with ALS, their families, and caregivers. During a visit, patients meet with several members of the multidisciplinary team, which includes five neurologists, two pulmonologists, and a team of experts that provides genetic counseling, occupational therapy, speech therapy, respiratory therapy, dietetic counseling, and the coordination of clinical trial studies. Free parking is available for patients during their appointments.

#### **Tissue Bank**

The ALS Tissue Bank, located in the Neuromuscular Disorders Program at Northwestern University Feinberg School of Medicine, collects and preserves brain tissue and spinal cord tissue from patients with a clinical diagnosis of ALS. By examining the motor neurons and other cells of the human brain and spinal cord, where ALS begins, researchers at the Les Turner ALS Research and Patient Center can better understand the factors involved in ALS. The Tissue Bank is an essential part of ongoing research.



Through the Les Turner ALS Foundation's Home and Community program, specialized services are available to patients and their families. Some of the services offered include the opportunity to schedule home visits with a Patient and Family Advocate who provides valuable disease information and help with continuity of care; communication devices or durable medical equipment from its equipment bank; a patient resource guide and other personalized programs. For more information, please contact the Les Turner ALS Foundation at 847-679-3311 or lesturnerals.org

Dr. Robert Sufit (center) with colleague Dr. John Michael Li and patient.

# THROUGH NORTHWESTERN MEDICINE, WE ARE CREATING A NATIONAL EPICENTER FOR HEALTHCARE, EDUCATION, RESEARCH, COMMUNITY SERVICE, AND ADVOCACY.

## **NORTHWESTERN MEDICINE**

Northwestern Memorial HealthCare and Northwestern University Feinberg School of Medicine are seeking to impact the health of humankind through Northwestern Medicine. We aspire to be the destinations of choice for people seeking quality healthcare; for those who provide, support, and advance that care through leading-edge treatments and breakthrough discoveries; and for people who share our passion for educating future physicians and scientists. Our commitment to transform healthcare and to be among the nation's top academic medical centers will be accomplished through innovation and excellence. Through the new Les Turner ALS Research and Patient Center at Northwestern Medicine, we have an unprecedented opportunity to enhance the care provided to people with ALS today and in the future and to further scientists' understanding of this very challenging disease. We recognize that every positive contribution we have made to ALS discovery, care, training, and outreach has been made possible by donors who have continued to entrust us with their philanthropic support. We invite interested friends to join us in advancing our new Center through gifts of outright support and endowment.



LES TURNER ALS FOUNDATION

